

Sharing Information, Sharing Responsibility: Helping Health Care Consumers Make Informed Decisions

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ABSTRACT

The purpose of this paper is to discuss the need to provide access to information to support informed medical decision-making and to describe a working model for delivering such information. We report the findings on the users of an independent health information service (n=1083), including: who uses this type of service; the types of information requested; and, the benefits for individuals and health care organizations.

INTRODUCTION

The evolution of health care delivery in the U.S. is significantly affected by new developments in information technology. It is in this context that electronic access to published information plays an increasingly critical role in improving the quality and cost-effectiveness of medical decision-making [1]. With more than 200 electronic medical databases available through on-line services, and numerous CD-ROM products and "user-friendly" software interfaces, research-based decision-making is likely to be incorporated as a standard in the practice of medicine over the next five years and as a mainstay in managed care services. There are several efforts under way to train physicians and other health professionals to incorporate medical literature into the process of care [2,3,4]. However, little headway has been made to provide the same access to information to patients. Why is this the case?

Compliance vs. Collaboration

Consider the typical physician visit. The escalating costs and administrative burdens leave the average physician with approximately 12 to 15 minutes per office visit [5]. In this short time, she or he must examine, question, assess, select tests, provide instructions - with no time to act in educational or "informing" capacity.

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Embedded in the physician/patient interaction is a relationship dynamic called "compliance", which defines the physician as "expert" and the patient as a passive receptacle. A recent FDA poll reported that as many as 42% of patients surveyed did not receive instructions on the proper use of their prescriptions [6]. As Stanley Reiser, M.D., Ph.D. recently wrote in the *Journal of the American Medical Association*, "We [physicians] have done little to give the individuals the knowledge or responsibility to make health care choices. . . " [7].

On the other hand, collaboration in medical decision-making recognizes the patient as an active, interested, and responsible participant in the physician-patient relationship. This concept (initially formalized by Lawrence Weed in his Problem-Oriented Medicine approach [8]) considers both parties as expert sources and seekers of information. There is a plethora of research supporting the value of "enrolling" the patient in his or her health care through education - it increases adherence to treatment protocols, reduces recidivism, and leads to improved outcomes across a variety of conditions, age groups and types of interventions [9,10,11,12].

Information Explosion: Access and Obstacles

Given the changes in the delivery of medical care, more patients are seeking out information from sources other than their physician's office in order to fill the need to know more. And, there has been a corresponding growth of publications, resources (the National Library of Medicine lists over 15,000) and programs to service those needs [13].

Recent innovations in telecommunications have improved the capability for a non-medically trained individual to locate research findings on-line. However, it still remains a challenging endeavor to navigate the complexities and language of medical database searching in order to find information that is directly relevant to the person's concern. Some medical libraries of large hospitals and medical centers will provide patients with "Medline" searches upon request, but this service is typically not advertised. Furthermore, these in-house services are often the victim of budget cutbacks [14].

In 1991, in response to the growing demand for the latest medical information and the difficulties in obtaining it, an independent service was developed and advertised to the general public (and to health professionals and organizations) as a fee-for-service organization. As of March, 1993, we have conducted over 1250 searches for individuals. The purpose of this paper is to report findings describing: who calls, what kind of information is requested, the reasons for calling, and the perceived benefits of becoming an informed consumer.

METHODS

Description of the Service

Between November 1, 1991 and March 31, 1993, the Health Information Network (hence referred to as the Network) engaged in modest promotional efforts in the California North Bay area and throughout the United States via am radio interviews and brochure distribution. The service was primarily advertised to the general public, although health professionals and health-related businesses (HMO's, insurance companies, nutritional supplement companies) would also use it.

Most of the callers were from the general public and were unfamiliar with medical terminology and on-line database searching. A standardized reference interview was developed to inform callers about the procedures, record information necessary to conduct the search, and explain what the results would look like and how they could be used. A disclaimer, detailed explanatory materials, and a list of suggested "Questions to Ask Your Health Professional" [16] were enclosed with each search.

Participants

The individuals who utilized the Network were self-selected, i.e., they had heard or were told about the Network, were English-speaking, and had no cognitive impairment that would prevent the completion of the interview nor the ability to read the printed results. Of the original 1311 who requested information, data from 198 were not used (15%) because of incomplete information, and 30 (2%) because they were requests from businesses or non-health professional services, leaving a total of 1083 participants' records available for tabulation.

The Interview

Once an individual called, a trained staff member would record the type of inquiry, answer questions about the service, and conduct a reference interview to obtain sufficient information to conduct

an on-line search. The interview, which averaged about 9 minutes in length, began with the questions that would help the caller specify the kinds of information in which they were interested. Once the general topic area was identified (e.g., "kidney stones treatment"), a series of "keywords" were used to help focus on the specific aspect(s) of the disease, treatment, or substance. Examples of keywords included: "therapeutic effectiveness"; "adverse effects"; "complications"; or "prognosis". The staff person was trained to describe in lay terminology what these keywords meant. The staff member also confirmed the person's interest in searching for "medical" (i.e., allopathic, conventional, Western) or "non-medical" (i.e., "alternative", "unconventional", defined as nutritional supplements, herbs, Traditional Chinese Medicine [including acupuncture], homeopathy, diet regimens, herbs, chiropractic, osteopathic manipulation, homeopathy, massage and other body-work, and psychological/cognitive therapies). Age, date of diagnosis, medications, co-existing conditions were also noted. For searches where the user was female, we noted whether she was pre-, peri-, or post-menopausal. For cancer questions, we requested fairly detailed information about the type, location and stage of the cancer; how it was diagnosed; and the current and prior treatments the person was undergoing.

Once sufficient information was acquired, the staff member would formulate the question(s) and read it back to the caller for confirmation and pricing. She or he would then describe what kind of results to expect (i.e., summaries, abstracts, full-text articles), and when to expect them (5 to 10 working days). At the close of the interview, the staff member read a standard disclaimer:

"This is an independent service providing information from published sources, including computerized databases, reference books, professional journals, and other published materials. Our mission is to support informed decision-making. We make a conscientious effort to respond accurately to your request, but do not claim that the information is completely exhaustive. We do not offer medical advice, or instruction, or make diagnoses. The information we provide is not intended and should not be used to replace a health professional, but to be used in collaboration."

Follow-up

In most cases sufficient information was obtained at the time of the interview to conduct the search. Medical librarians (M.L.S.) trained in the use

of on-line databases conducted the searches.

Approximately 6% of the participants had to be re-contacted to get more detailed information. Upon completion of each search, a quality control review was performed to verify that the results adequately responded to the request.

Participants were encouraged (at the time of the initial inquiry and in a letter enclosed with the search results) to let the Network know if the information was of any value. A self-addressed postcard was included with each search requesting the following feedback on a 1 to 3 scale (Very much; Somewhat; Not at All):

1. Was the person who assisted you helpful?
2. Did the information respond to your request?
3. Was the information useful?
4. Would you recommend this to a friend?

Of the 1083 inquiries, 688 (64%) postcards/callbacks were received, with an attrition of 36%. No attempt was made to follow up these individuals.

Analysis

The purpose of this paper is to report on an telephone service operating to serve the need for information by a broad spectrum of individuals. We did not start out with the intention of designing a "study", and we recognize that people who utilized the Network were self-selected. No *a priori* attempt was made to create a sample whose data would be appropriate to explore statistically. Therefore, the results are presented in the form of percentages.

RESULTS

Characteristics of the Respondents

Of the remaining 1083 people who used the service, 54% were women and 46% were men. Seventy nine per cent (79%) were general public inquiries, 21% were health professionals.

Table 1 summarizes the results of the question: "Who is this for?" Almost half of the respondents (49%) were calling on behalf of themselves. Interestingly, 22% were calling for a friend or family member. Health professionals called primarily on behalf of their patient or client. Some professionals called for their own research or professional interests, but these accounted for about half of the "Research/Professional Use" category. The other half were general public callers doing research for a paper or personal knowledge - without a specific individual in mind.

Table 1. Information User

User	Per cent
Self	49
Friend or Family Member	22
Patient/Client	16
Research/Professional Use	10
Unknown	3
n=1083	

Table 2 summarizes the results of the questions: "How did you hear about the Network?" Again, almost half (48%) saw or heard about the service through an advertisement or promotion. Approximately two-thirds of this sub-group (n=347) heard about the Network listening to radio health-oriented talk shows on which a Network representative was a featured guest. About 12% (n=130) stated that they called the service "because a friend/family member suggested it", suggesting a "word-of-mouth" referral mechanism that may be part of an individual's "need to know more".

Table 2. Source of Referral

Source	Per cent
Advertisement	48
Health Professional	15
Personal (friend or family)	12
Other	7
Did not remember	18
n=1083	

Patterns of Use

Tables 3 and 4 summarize the kinds of requests for information the participants made. The categories in Table 3 were based on the National Library of Medicine's Medical Subject Headings Subcategories [15]. In the "Neoplasms" category, 37% of these inquiries (n=60) were for information on Breast Cancer, and 15% were for Prostate Cancer (n=24). In the "Infectious Diseases" category, 36% of the requests were for information on Chronic Fatigue Syndrome. And, in the "Women's Health" category, 22% (n=21) were requests for Pre-Menstrual Syndrome information, and 27% (n=26) were requests for Menopause information. The rest of the topics in each category were distributed over a wide variety of subject areas, with no one subject area being predominant. It should also be noted that the

category "Diet Therapy & Nutritional Supplements" reflects the participants' interest in the general benefit of a particular supplement (vitamin, herb) or nutritional approach (vegetarian diet), rather than its effect on a particular condition.

Table 4 summarizes the kind of information the caller was most interested in obtaining. "Consumer packages" emphasize summaries and articles from the popular literature as well as refereed medical literature and cover a variety of subjects on a particular medical condition. These were requested most frequently, as a means of becoming familiar with a subject area, and 4% of the individuals requesting this type of information called back with a more specific request.

Table 3. Requests for Medical Conditions

Condition	Per cent
Neoplasms	15
Infectious Diseases & Viruses	13
Nervous System Disorders	10
Women's Health Problems	9
Musculoskeletal Conditions	6
Skin Conditions & Diseases	6
Diabetes & Diabetes-Related Conditions	6
Cardiovascular Conditions	6
Back Pain & Soft Tissue Injury	5
Respiratory Conditions	5
Digestive System Disorders	5
Diet therapy & Nutritional Supplements	4
Urologic & Male Genital Diseases	4
Other	6
n=1083	

Table 4. Type of Question

Type of Question	Per cent
Consumer Package	22
Non-Medical Treatment	18
Medical Treatment - Options & Effectiveness	13
Etiology, Definitions, Diagnosis	13
Adverse Effects & Complications	8
Comprehensive	8
Prognosis	7
Full-text Retrieval	5
Medical & Non-Medical Treatment	4
Other	2
n=1083	

Several aspects of medical (defined as surgical or chemo/pharmacological or radiation interventions) treatment information were requested, including "Effectiveness", "Etiology", "Adverse Effects and Complications", and "Prognosis". And, 8% of the callers requested a "Comprehensive Package", which covered all of these topics. Together, these comprised 49% of the requests. "Non-Medical Treatment" information was requested by 18% of the callers, and another 4% were interested in both medical and non-medical approaches.

Satisfaction with the Results

About 36% of the callers did not respond with follow-up information. As indicated in Table 5 (shown on next page), results of this modest follow-up effort suggest that the majority of the individuals who responded were pleased with the information as well as the quality of the service. These results further suggest that, even when the information was "moderately useful", the participants valued the process and the result enough to want to recommend it to a friend.

DISCUSSION

As a result of our initial efforts to provide information on often complex and challenging questions to non-medically trained individuals, we found that there is indeed an interest (and in some cases a demand) to become more informed. This is particularly relevant in light of the movement away from the traditional "doctor-patient" relationship and toward managed care.

It should be recognized that the patient as well as the provider has a vested interest in research-based decision-making. Other reports have described how using medical literature can positively impact the provider [2,3,17]. There is evidence from these data that there are health care professionals who will utilize independent services to access to medical literature (21%, n=227), and that there are also those who will refer their patients (15%, n=163). Further, our experiences strongly suggest that some patients want to become their own "experts", whether it be "in collaboration" or not.

In responding to requests for information, we also heard numerous comments from callers indicative of how valuable research delivered to the consumer can be. Although the staff did not formally inquire, many of the callers spontaneously mentioned the frustration and fear when asked to make a choice (or "go along") with a particular regimen in absence

of having a clear understanding of the impact it could have on their immediate and long-term well-being. We also heard reports of how some individuals were afraid to take the information back to their doctors, for fear of being perceived as "questioning his authority" or "getting her angry".

In sum, providing relevant information directly to the consumer is a low-cost way to enroll the cooperation of the patient in the decision-making process. The information can be read and digested after the medical visit. Information can facilitate the

individual regaining a sense of control about their health and their choices, and reduce some of the stressfulness that occurs when dealing with a serious medical problem.

Organizationally, the integration of on-line medical information into routine operations can improve efficient decision-making as well as the quality of care [2,8]. This low-cost approach offers tremendous opportunities for improving the communication between provider and patient and enhancing organizational effectiveness.

Table 5. Satisfaction With Results

	Percent			
	Very Much	Some what	Not at All	Unknown
Was the staff person helpful?	72	19	7	2
Did the information respond to your request?	66	24	8	2
Was the information useful?	45	35	19	2
Would you recommend this to a friend? (Yes/No)	83	n.a.	12	5

n=688

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